

I. Summary

A. Background

Between the months of November 2000 and August 2001, Public Health - Seattle & King County's HIV/AIDS Program and the HIV/AIDS Planning Council for the Seattle Eligible Metropolitan Area (EMA) conducted a comprehensive needs assessment of HIV/AIDS care services in King County. Quantitative epidemiological data, including current infection and case trends, had already been collected and analyzed by Public Health's HIV/AIDS Epidemiology Program and were used in this comprehensive process.

The 2001 Needs Assessment was a research and planning activity that sought to:

- identify the extent and types of existing and potential care service needs among persons living with HIV/AIDS in King County
- examine the current service delivery system in the County, particularly the system's ability to ensure that persons living with HIV/AIDS can effectively obtain and maintain access to primary medical care
- determine the extent of unmet needs or underutilized resources in order to plan appropriate care services
- analyze and compare two-year trends in service utilization, priorities, gaps and access barriers

The main objective of the 2001 Needs Assessment process was to provide data to inform decisions related to the Planning Council's prioritization of care services for the Ryan White CARE Act's Title I funding allocation process. (See Appendix A for a list of Planning Council- approved Ryan White service categories.) Additional goals of the project were to:

- assess the current Continuum of Care in Seattle-King County, with the goal of strengthening the system and working towards greater collaboration among diverse communities and service systems;
- provide legislatively mandated information to the federal Health Resources Services Administration (HRSA) on service needs and system response, and
- provide planning information for agencies, organizations, and health care providers

Efforts were made to collect information from as wide a spectrum of persons living with HIV/ AIDS in King County as possible, ranging from individuals who were are HIV positive but not yet symptomatic to persons with end-stage illness. Traditionally under-served populations were given particular focus, including persons who were homeless, those who were dually or triply diagnosed (with HIV, mental illness and/or chemical dependency), women, youth/young adults, persons of color, and persons living in South and East King County.

This HIV/AIDS Needs Assessment provides a “snapshot” of community services, priorities, gaps and access barriers as identified by consumers and providers in 2001. By nature, needs assessment processes must be ongoing to reflect the changing nature of the service delivery system, treatment advances, funding availability, and epidemic trends. Public Health - Seattle & King County, in conjunction with the Planning Council, is currently planning future needs assessment projects that will augment the findings of this most recent process.

B. Methods

Several strategies were employed to solicit input in the needs assessment process:

- creation and distribution of written surveys to persons living with HIV/AIDS (PLWH) throughout King County (538 valid surveys returned)
- creation and distribution of written surveys to providers of HIV-related services throughout King County, including medical, dental, mental health, substance use treatment, and support services (256 valid surveys returned)
- key informant interviews with 28 service providers
- focus groups conducted with 11 sub-populations of PLWH

Public Health - Seattle & King County (Public Health) has conducted several other needs assessment processes related to HIV/AIDS care services during the past two years. These include:

- The 2000 “Not in Care” Interview Project, a focused assessment process conducted by the Planning Council and Public Health that attempted to interview PLWH who, for whatever reasons, were not accessing primary outpatient medical care for their HIV infection. (See Appendix B for summary data from the “Not in Care” Project.)
- The 2000 HIV/AIDS Care/Prevention Collaboration Project, that explored whether HIV prevention providers in Seattle-King County appropriately refer their HIV+ clients into care services and whether HIV care service providers discuss sex and drug use risk reduction with clients and make appropriate referrals for clients with ongoing risk reduction needs. (See Appendix C for a summary article on the project, reprinted from the Washington State/Seattle - King County HIV/AIDS Epidemiology Report, 1st Half 2000.)
- The 1999 Comprehensive Needs Assessment, which employed similar data-gathering strategies as the current process to identify consumer- and provider-identified service utilization rates, service priorities, gaps in services, and barriers to accessing services.

C. General Findings from the 2001 Needs Assessment

As in previous assessments, most service providers report that their caseloads are comprised primarily of gay, white men. This is particularly true for general medical providers and staff at AIDS service organizations. However, trends that first emerged in 1997 continue. Providers from across the Continuum of Care report increases in the number of clients seen who are women (from 13% in 1999 to 18% in 2001), persons of color (from 27% in 1999 to 29% in 2001), heterosexual injection drug users (from 11% in 1999 to 15% in 2001) and clients who live outside of Seattle (from 19% in 1999 to 23% in 2001). Providers also noted increases in the numbers of clients who are dually and/or triply diagnosed (with HIV, mental illness and/or chemical dependency).

Providers report that the majority of their clients have good access to medications and are responding well to the treatments. However, providers increasingly report that they are seeing more clients who are not responding as well to their HIV medications as they did several years ago. This translates into increasing numbers of clients who are developing opportunistic infections and requiring intensive medical care. Providers also noted an increase in AIDS-related mortality, reversing a trend in significantly decreased mortality that had begun in the mid-1990's.

Providers also reported ongoing increases in the numbers of clients who are presenting with mental illness. Each of the 28 providers interviewed as part of the key informant interview process noted that depression is on the rise among their caseloads. The overall percentage of clients that providers reported as presenting with mental illness rose from 32% in 1999 to 47% in 2001. Providers also reported that more clients with severe mental illness continue to enter the care service system, including increasing numbers of clients with personality disorders and psychoses. Providers note that serving these clients is very time and labor intensive, requiring greater coordination than ever between the HIV and mental health systems.

Providers also noted that they are seeing an increase in the number of clients for whom English is not their primary language. In 1999, providers reported that an average of 3% of their caseloads were primarily Spanish speaking. By 2001, that figure had risen to 5%. Providers also reported seeing increasing numbers of West African refugee PLWH, particularly clients from Ethiopia and Eritrea.

In general, consumer focus group participants expressed satisfaction with the quality of most of the services offered in the King County Continuum of Care. In particular, consumers noted that medical care was available to them and their peers when they chose to access it and that the quality of care they received was excellent. The very small number of consumers who were not currently using medical care or taking HAART medications stated that this was by personal choice, not due to lack of access to care.

Concerns about case management arose more frequently in the 2001 assessment process than in any of the previous needs assessments. Two issues were highlighted:

- **Lack of case managers of color:** Consumers of color often expressed concerns about what they viewed as a lack of culturally sensitive case management services. Although most of the focus group participants felt that their case managers were doing an adequate job in assisting them, concerns were raised regarding case managers' abilities to comprehend and respond effectively to the cultural norms of non-white consumer populations. As several consumers and key information providers noted, it is becoming increasingly important for case managers to be bicultural, not merely bilingual.

- Lack of service continuity: Consumers from across the spectrum of sub-populations were frustrated by the frequency of staff turnover in case management agencies. Focus group participants, particularly men who have sex with men (MSM) and residents of South and East King County, noted that it was very difficult to maintain trust and develop working relationships when the person assigned as their case manager kept changing. Some consumers reported having had four or five case managers since 1995, due to staff attrition.

Consumers also expressed dissatisfaction with what they perceive to be decreasing availability of volunteer-driven services. These include home chore services, transportation, food and meal delivery and one-on-one peer support. This concern was voiced most frequently by consumers of color and non-Seattle residents. Consumers noted that it was often difficult to recruit and maintain volunteers from their communities and that this has had a negative impact on their access to these services.

D. Service Utilization

Utilization rates were highest among survey respondents in the areas of primary medical care, client advocacy programs, case management, and dental care. Use of services among survey respondents has remained relatively constant in most categories during the past few years, although several significant changes have emerged since 1999. Use of case management services has risen significantly, increasing from 72% of respondents in 1999 to 79% in 2001. Significant increases were also seen in use of insurance programs (up from 50% in 1999 to 57% in 2001) and mental health therapy and counseling (up from 43% to 49%). No significant utilization decreases were noted in any service category during the past two years.

Several differences emerged regarding utilization patterns reported by sub-populations of PLWH on the consumer survey. Although few differences emerged related to gender, male PLWH were significantly more likely than females to use case management services (81% versus 67%), while females were more likely to use substance use treatment and counseling (25% versus 15%). Reported service utilization by PLWH who are injection drug users (IDU) was greater than non-IDU in several categories, most notably case management (87% of IDU versus 77% of other consumers), housing assistance (62% versus 42%) and food and meal programs (60% versus 46%).

Greater differences emerged in the utilization of most services based on race than in past assessments. In general, African-American PLWH reported higher utilization rates than white PLWH. These differences were most significant in the areas of transportation services (50% versus 29%), peer emotional support counseling (66% versus 55%), emergency financial assistance (48% versus 38%) and housing assistance (61% versus 50%). Conversely, utilization rates among white and Latino/a PLWH were relatively similar. Due to the small number of American Indian and Asian/Pacific Islander survey respondents, it is not possible to make similar statistical comparisons.

In previous years, a significantly lower percentage of East and South King County consumers reported currently accessing outpatient medical care and other clinical services in comparison to Seattle residents. Although non-Seattle residents reported higher rates of medical care utilization than in prior years, the percentage remains lower than for Seattle consumers (91% versus 96%). Utilization rates for other services are relatively similar, with the exception of insurance programs (used by a greater proportion of non-Seattle residents: 64% versus 55%) and mental health therapy and substance use counseling (used by greater percentages of Seattle PLWH: 51% versus 39% and 19% versus 5%, respectively).

As noted in previous assessment reports, homeless PLWH exhibit utilization rates which are similar in most respects to other consumers once they enter the care system. Providers noted that their homeless clients use a wide variety of available services, with increased utilization of case management, mental health and chemical dependency treatment than in previous years.

E. Service Priorities

Consumers ranked primary medical care as the highest service priority, followed by dental care, case management, housing assistance and housing related services and insurance programs. Relative priority rankings changed little between 1999 and 2001 for most services. Drug prescription programs, ranked as the top consumer priority in 1999, dropped to the sixth highest priority (ranked as a priority by 62% of consumers in 1999 and 40% in 2001). Conversely, consumers were more likely in 2001 to prioritize insurance programs, which moved up from eighth to fifth in the priority rankings (34% in 1999 and 41% in 2001). Food and meal programs dropped from the sixth highest priority in 1999 (35% listing the service as a priority) to a tie for tenth in 2001 (29%).

In addition to the aforementioned services, three other categories experienced significant changes in the overall percentage of consumers who listed them as priorities between the two survey years. These included ambulatory medical care, legal assistance and mental health therapy/counseling. Sixty-three percent of respondents prioritized ambulatory care in 2001, up from 55% in 1999. The percent of consumers who prioritized mental health therapy also increased, from 23% in 1999 to 29% in 2001. Legal assistance was significantly less likely to be listed as a priority, dropping from 21% of respondents in 1999 to 16% in 2001.

Providers ranked ambulatory care as the highest service priority for their clients, followed by case management, mental health therapy/counseling, drug prescription programs, and substance use treatment/counseling. Similar to previous years, providers were significantly more likely than consumers to prioritize substance use treatment (49% versus 9%) and mental health counseling (63% versus 29%). This discrepancy was noted by providers during the key informant interview process, many of whom reported increases in the incidence of dual and triple diagnoses (HIV/mental illness/chemical dependency) among their client populations, coupled with consumer resistance to and/or lack of access to these services.

MSM survey respondents were statistically more likely than other consumers to prioritize clinical services, such as primary medical care (67% of MSM versus 49% of non-MSM), dental care (59% versus 45%) and mental health therapy and counseling (31% versus 18%). Conversely, MSM were less likely than other consumers to prioritize support services such as emergency financial assistance (28% versus 39%), food and meal programs (25% versus 36%), housing assistance (44% versus 60%) and client advocacy (33% versus 43%).

Continuing a trend first observed in 1995 and continuing in recent years, persons of color were significantly more likely than whites to prioritize housing assistance (55% versus 40%). Providers noted that many of their clients of color were living in low income housing prior to their AIDS diagnoses, often with family members who are no longer able to care for their medical needs. For immigrant or refugee PLWH, such as the emerging number of non-resident Latino/a PLWH and PLWH from West African, the need for housing is also crucial.

Consumers of color were also significantly more likely than whites to prioritize client advocacy services (45% versus 29%). PLWH of color who attended focus groups noted that verbal and written information about HIV disease and medications is difficult to obtain within their communities. Consumers of color stressed the importance of peer advocacy programs, from which they could learn about access to the system from persons who understand their language and cultural norms.

Female and male PLWH reported more similarities than differences in service prioritization. Nevertheless, several services were more highly prioritized by women than men, including housing services (60% versus 45%), client advocacy (particularly peer advocacy) (50% versus 33%) and peer emotional support (40% versus 26%). Women were significantly less likely than men to prioritize clinical services, such as primary medical care (45% versus 67%), dental care (39% versus 58%) and drug prescription programs (29% versus 41%).

Geography did not appear to play a major factor in the ways in which consumers prioritized most services. However, East County PLWH were more likely than Seattle and South King County consumers to prioritize telephone referral programs (29% versus 8% and 9%, respectively) and less likely than other consumers to prioritize primary medical care (46% versus 64% of Seattle PLWH and 63% of South County PLWH).

F. Service Gaps

Consumers identified lack of access to emergency financial assistance as the number one service gap (services which consumers stated they needed, but could not get). Almost one quarter of survey respondents identified this gap. Among the sub-components of this service category, 19% of respondents identified a gap in help paying utility bills and 16% identified a gap in help paying for groceries.

The only other service that was ranked as a gap by more than a 20% of survey respondents was housing assistance and housing related services. Of the component services in this category, 14% of consumers identified a gap in rental assistance and 13% reported that they needed but could not get help in finding housing.

Other services that ranked among the top five service gaps for consumers were client advocacy programs, peer emotional support, and food and meal programs. Within the client advocacy category, the largest gaps were reported in the non-case management financial benefits counseling (identified as a gap by 11% of consumers) and peer advocacy (10%). In the emotional support category, the largest gaps were identified in one-on-one peer support (14%) and support groups (12%).

As in previous years, outpatient medical care continued to be identified as a gap by a very small number of consumers. Only 1% of survey respondents (6 out of 538) stated that they needed but could not access outpatient medical care. Five percent of consumers reported that they needed but could not access Washington State's AIDS drug assistance program.

The top five services which providers identified as lacking for their clients were housing assistance and housing related services, substance use treatment and counseling, mental health therapy and counseling, client advocacy and dental care. Providers also noted that outpatient medical care was not a large gap for the clients, with only 2% of providers identifying a gap in provision of this service.

MSM were fairly consistent with other populations in ranking service gaps. However, significantly lower percentages of MSM identified gaps in access to emergency financial assistance (22% versus 34%), food and meal programs (8% versus 18%), and case management (3% versus 9%). In general, MSM of color were more likely than white MSM to report gaps in the provision of services. MSM of color were almost twice as likely as white MSM to identify gaps in housing services (29% versus 15%). Other key differences emerged in the areas of peer counseling (27% versus 17%), legal assistance (18% versus 8%), and adult day health (15% versus 2%). Within the category of peer counseling, the largest gap emerged in one-on-one peer support (24% versus 11%), with particularly large gaps noted by Latino MSM.

Continuing a trend first reported in 1999, IDU survey respondents were less likely than other consumers to report unmet service needs. The only service that was statistically more likely to be identified as a gap by IDU than by non-IDU PLWH was substance use treatment (12% versus 3%). As noted by providers, once they enter substance use treatment or counseling, IDU PLWH seem to exhibit utilization rates of HIV-related services that are very similar to other consumers. However, a significant number of HIV+ IDU are not currently receiving care for their substance use and may forego using HIV-related services until they feel ready to address their chemical dependency issues.

Persons of color were significantly more likely than white PLWH to identify gaps in almost one third of all service categories. The greatest disparities in access emerged in the areas of adult day health programs (15% versus 2%), housing assistance (27% versus 16%), telephone referrals to care (17% versus 6%) and peer support counseling (27% versus 17%).

In comparison to previous surveys, differences in service access based on gender were reported in very few service categories. However, 32% of female respondents noted difficulty in accessing emergency financial assistance, as compared to 22% of males. Women were also more likely than men to identify gaps in housing assistance (25% versus 18%) and in food and meal programs (21% versus 8%).

Very few differences in access to services emerged related to geography (East and South King County PLWH versus Seattle PLWH) or homeless status. As expected, homeless consumers were far more likely than non-homeless persons to report gaps in housing assistance and related services, particularly help in finding low income housing.

G. Access Barriers

Similar to previous assessments, the two main barriers identified by consumers in accessing services were lack of information about available services and inability to afford services. The percentage of consumers who identified being unable to access services due to disability-related eligibility criteria, lack of comfort in agency settings, and lack of geographic access to services decreased significantly from 1995 to 1999, and remains low in 2001.

The identification of access barriers was remarkably similar across the spectrum of PLWH sub-populations surveyed. However, focus group participants and service providers noted that cultural and economic factors continue to inhibit certain clients from accessing the services they need. These include language barriers for clients with limited or no English language proficiency, cultural norms about seeking medical care and taking medications, chaotic lifestyles, and unstable living situations.

Providers also noted that co-morbidities can severely hinder their clients' abilities to access needed services. These include mental illness, active substance use and histories of incarceration. Unfortunately, providers also noted that the percentage of clients on their

caseloads who are dually or triply diagnosed has increased, leading to greater difficulties for increasing numbers of clients in obtaining services and increased provider time and energy required to assist these clients.

H. Access Services

In response to the Health Resources and Service Administration's increased focus on medical care access and engagement, the Planning Council added a new component to the 2001 consumer and provider surveys. The 2001 survey asked consumers and providers to identify the services they felt were most important in helping them or their clients access or maintain medical care ("access services").

In general, consumer rankings of access services were extremely similar to their rankings of service priorities. Consumers identified case management as the most important service in helping them get or maintain medical care, followed by insurance programs, dental care, client advocacy, Washington State's AIDS drug assistance program and housing assistance.

Providers were in agreement with consumers regarding the importance of case management in helping PLWH access medical care, also ranking it as the highest access services. Providers also ranked client advocacy and prescription drug programs among their top five access services. However, consistent with divergent provider/consumer opinion about the importance of mental health and substance use counseling, providers ranked these services as the third and fourth highest priorities, while consumers ranked them 8th and 19th, respectively.